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Black women of low-socioeconomic status (SES) demonstrate a higher incidence of breast cancer mortality associated with late-stage diagnosis than White women. Breast cancer screening, including mammography, breast self-examination, and clinical breast examination, remains the most effective route to early detection. Studies indicate poor adherence to breast cancer screening regimens among low-income minority women. An overall objective of the study is the construction of a theoretical model that can explain screening practices in low-SES black women. This will be accomplished in two separate waves. In the first wave, facilitators and barriers to breast cancer-screening participation among low-SES women of African-American and Caribbean descent will be determined through qualitative interview. This approach allows a voice for the concerns and experiences guiding these women in their screening choices. The current study incorporates an approach-avoidance theoretical framework that considers preventive screening behaviors to be both desirable and aversive. Based on the factors provided by respondents on the first wave of the study, a culturally sensitive Q-Sort instrument will be designed that will allow participants to rank order these factors as facilitators or barriers to screening, and therefore, provide a powerful approach to testing the theoretical paradigm. Finally innovative modeling techniques will be applied to determine the strength of emergent models to explain breast health care practices among low-SES Black women, either as idiopathic to the general population or specific to African-American or Caribbean cultural groups.

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breast cancer screening, mammography, breast self-exam, access to Care, phychosocial barriers to care, minority populations

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Table of Contents

Introduction

Black women of low-socioeconomic status (SES) demonstrate a higher incidence of breast cancer mortality associated with late-stage diagnosis than White women. Breast cancer screening, including mammography, breast self-examination, and clinical breast examination, remains the most effective route to early detection. Studies indicate poor adherence to breast cancer screening regimens among low-income minority women. An overall objective of the study is the construction of a theoretical model that can explain screening practices in low-SES black women. This will be accomplished in two separate waves. In the first wave, facilitators and barriers to breast cancer-screening participation among low-SES women of African-American and Caribbean descent will be determined through qualitative interview. This approach allows a voice for the concerns and experiences guiding these women in their screening choices. The current study incorporates an approach-avoidance theoretical framework that considers preventive screening behaviors to be both desirable and aversive. Based on the factors provided by respondents on the first wave of the study, a culturally sensitive Q-Sort instrument will be designed that will allow participants to rank order these factors as facilitators or barriers to screening, and therefore, provide a powerful approach to testing the theoretical paradigm. Finally innovative modeling techniques will be applied to determine the strength of emergent models to explain breast health care practices among low-SES Black women, either as idiopathic to the general population or specific to African-American or Caribbean cultural groups.

Report Body

Research accomplishments are presented in a temporal sequence to provide a description of the evolution of research tasks and the context in which they occurred. Embedded in this sequential structure is a discussion of research accomplishments that fall into two general categories: infrastructure and IRB issues and accomplishments of a formative nature.

I. Infrastructure and IRB Issues

Coinciding with the beginning of this grant, two site-related issues impacted getting the study underway. First, it was the expectation of the Dental School at the University of Medicine and Dentistry of New Jersey (UMDNJ) that my study would be embedded in a larger population-based study proposed by Dr. Theresa J. Jordan. It was this mother grant that provided my access to necessary staff, a research space that would be available to me for the remainder of the study, and the full cooperation of school and department heads. When this population-based grant was not funded, there was no longer any person contractually involved at the site as all support and approval documented in the letters included in my grant proposal were directly related to Dr. Jordan's intended study. Efforts to reestablish infrastructure would need to begin from the very beginning. At the same time, the Dental School experience major turnover in top leadership positions. It was necessary to hold repeated meetings with top-level people whose familiarity with and approval for the study was required. A great deal of time during all of year one and a portion of year two were taken up in these tasks. Going into the current report period, these two tasks were successfully addressed.

Also as stated in the approved Statement of Work, Internal Review Board clearance was required from both New York University and UMDNJ. The NYU IRB has been submitted and

confused as to the actual forces preventing me from submitting and realize that much time has passed and I still have not begun data collection.

As far as my NYU IRB, I submitted an annual continuation packet to NYU on February 5th. NYU had previously granted approval pending approval from UMDNJ. The most current packet was approved pending approval from UMDNJ and also asked for two slight revisions, which were made and resubmitted. I await hearing from the Office of Sponsored Research at NYU.

II. Accomplishments of a Formative Nature

Three tasks were performed this past year that are of a formative nature. The protocol for the qualitative interviews was developed, all quantitative instruments were piloted, the SPSS dataset was modified to address any modification made to survey items, and my literature was updated to include current articles in my topic area as well as consideration of the current controversy surrounding the efficacy of mammography.

Development and Piloting of Qualitative Interview Protocol:

The qualitative interviews will be the first phase of data collection. In order to allow the experiences of respondents regarding breast health care practices to emerge, a semi-structured open-ended format will be used. The protocol places certain structures on the content of the interview, while allowing the researcher to apply prompts to elucidate the respondent's narrative. Refer to **Appendix A** for the Research Interview Protocol. In November 2001, this protocol was piloted on three women to assess the clarity of the questions. Three Black women working in the principal investigator's community volunteered to sit with the reviewer and answer these questions. They were instructed, at the onset, to please let the interviewer know when a question

decided that we would follow this course of action. Nothing would change in terms of my patient population, but the IRB would reside at the School of Public Health. It was decided that both Dr. Montgomery and myself would meet with appropriate personnel at the School of Public Health to receive permission and discuss any changes required from my existing IRB packet.

Unfortunately, over the course of the summer that meeting never took place despite my repeated communications to Dr. Montgomery. By the end of the summer, with the Dental School now closed until the fall, Dr. Montgomery informed me that things had eased at the Dental School and with my own adjustments made to the patient records issue, I'd be able now to submit to the Dental School as originally planned. Meetings were scheduled for September 2001 to address any changes required of my IRB packet. With the occurrences on 9/11, many of these meetings needed to be rescheduled several times throughout the fall. At the same time, Dr. Montgomery became unavailable often through the fall of 2001 and I have since attributed that to fallout from 9/11.

Towards the end of the fall, Dr. Montgomery suddenly notified me that prior to IRB submission, I would need to pilot my instruments and make any necessary revisions to them. He wanted to be able to go to Dental School personnel with evidence of my being able to start data collection immediately upon IRB approval. My efforts at piloting instruments had begun prior to this and will be discussed in the next section. With the beginning of 2002, all piloting tasks were complete, but I still did not receive word regarding IRB submission. While waiting, I downloaded all IRB documentation from the UMDNJ website and rewrote my IRB packet because a year had gone by and I knew I needed to update my forms. Dr. Montgomery told me that once submitted, the IRB would turnover in three days. It appears that I would get an automatic exemption from UMDNJ as my study is viewed by the institution as a non-invasive survey design. As I prepare this report I must say that I still await word from Dr. Montgomery on IRB submission. I am

conditionally approved twice annually pending approval from UMDNJ. For site-related reasons, the principal investigator has not been able to submit a packet or receive approval from UMDNJ. This has continued to be a great source of frustration.

First, there was an overhaul of IRB protocol at UMDNJ, which caused the freezing of any IRB submissions. This moratorium was lifted around 2/01. For the next 3-4 months I awaited word from my on-site mentor, Dr. Richard Montgomery, that my completed IRB packet could finally be submitted for approval. Then, prior to the end of the Spring semester, my on-site mentor informed me that the Dental School was no longer allowing studies requiring the abstraction of medical records to be approved or conducted. They were also less than enthusiastic, suddenly, about any IRB approval for studies conducted by outside researchers. On June 25th, I contacted my contract specialist at DOD, Kathy Dunn, to apprise her of these issues via email. I initially required access to patient records for two purposes: 1) to access information required for exclusionary criteria of potential participants; 2) for information regarding general medical health and access to health care. This dilemma was addressed in two ways. First, because I had developed an instrument to measure access to health care in the previous funding year, I no longer needed patient records to access this information. I also developed a quick patient criteria form that would easily detect those women who were to be excluded from my study (exclusionary criteria include age less than 40 and a family history of breast cancer). I now no longer needed to access patient records. Second, UMDNJ was accredited in May 2001 to open a new School of Public Health, where my on-site mentor was given a joint appointment as Associate Professor. Considering the social science and epidemiological orientation of my study, it seemed appropriate now to channel my IRB proposal through the School of Public Health. In June 2001, I met with both Dr. Jordan (my supervising mentor) and Dr. Montgomery (my on-site mentor) and it was

was either unclear or not important to their breast cancer screening experiences. See **Appendix B** for Summary of Interview Pilot. At the same time, the interviewer noted any questions that were eliciting only yes/no types of responses. The time it took to conduct the interview was also noted. It is the intent of the investigator to not go much beyond 40-45 minutes in length to ensure that the respondent is engaged in the interview in a way that promotes valid data collection. As noted in Appendix B, the interview protocol provided in **Appendix A** reflected any modifications made as a result of this piloting and represents the current version of the protocol.

Piloting of Quantitative Instruments:

The next task to be reported was the piloting of the quantitative instruments. Four quantitative self-report measures will be used in the study. Refer to **Appendix C** for copies of current instruments. Three of them are existing measures located in the literature. They include: Intent to Breast Cancer Screen (modified from Saint-Germain & Longman, 1993), Screening Beliefs Scale (Champion & Scott, 1997), and Breast Cancer Screening Practices (Saint-Germain & Longman, 1993). One measure was developed by the principal investigator for the current study and is called the Access to Health Care Survey. The purpose of this survey is to gather information regarding factors that impact access to health care among low-income underserved populations.

The rationale behind this decision emerged in Spring 200 from engagement in the ongoing process of literature review. During this process, critical studies were identified, alerting me to dimensions to be targeted in this instrument. This pre-doctoral study is motivated and informed by the discrepancy in breast cancer mortality and levels of screening practices between low-income minorities and other middle, and upper class populations. Several current government initiates, including the Department of Health and Human Services ongoing Health People 2000 and Health People 2010, the DHHS Division of Health Promotion and Disease Prevention's Final Report on

"Leading Health Indicators for Healthy People 2010 (1999) indicated that much of these discrepancies in health prevention behavior and health outcomes can be traced to the discrepancies in health care access experienced by underserved populations. As such, development of this instrument began in early January 2000. The full instrument was completed in its tentative version prior to this year and piloting of this instrument occurred in Summer 2001. Cognitive testing of the instrument among medical professionals was undertaken last year and this year, the instrument was piloted on a small number of women for question clarity and content.

Three women agreed to sit down at separate times with the investigator to review the content of the Access to Health Care Survey. All women were white, middle class females living in New York City. At the time of piloting, the investigator was unable to access low-income women of color. These women were asked to listen to each question and provide a response. They were told that in doing so, to please pay special attention to three questions: 1) Is this question unclear; 2) Would you change anything about the response choices to these questions; and 3) Can you think of any questions that you believe should have been asked but weren't.

As a result of this piloting, several changes were made to the instrument. These changes fall basically in two areas: additional items were added, and response choices for several existing items were modified. The current version of this scale now contains 74 items as opposed to the old version with 67 items. Item 36 was added, "Do you have any problems with your health coverage"; after two women volunteered information regarding this when answering item 35. Item 48 was added, "How much average time does a medical appointment take from the moment you leave for the appointment to the moment you return?" It was decided that cost in time should be tapped as well as cost in dollars. Item 49 was added, "Besides the cost of the medical visit, on average, what is the financial cost to you to get to an appointment?" (Prompts include: carfare, bus

or train fare, childcare, lost time from work). This item was added after one woman pointed out that costs incurred could go beyond any payment for services rendered. Item 63 was added, "I would feel better about my medical care if my health insurance carrier would....". Two other existing items ask respondents to fill in the blank to "I would feel better about my medical care if..." or "I would feel better about my medical care if my health care provider would...." Two women provided information on health insurance carrier to second item, so item 63 was added to get at health insurance issues. Finally, Item 73 was added, "When I go for medical care, the office staff usually treats me with respect" after remarks about the medical staff were referred to when interviewer asked about respect of medical doctor.

Several changes in item response choices also resulted from this pilot. Item 30 now asks how long one has been on their current health care plan. Items 33-35 now include "None" and "Other" as additional response choices. For item 35, "What is the biggest problem when attending the doctor's appointment?", "being sent for additional lab work" and "problems with health insurance" were added as additional response choices. Item 46, "How did you get to your appointment today?", now provides specific response choices that include: "drove myself", "cab", "bus", "train", "got a ride", "walked", "ambulette", or "other".

The same three women also participated in a pilot of the three existing measures to be used in the study. Only the Screening Beliefs Scale (Champion & Scott, 1997) was modified. Under the items related to mammography, item 11 stated, "I have other problems more important than getting a mammogram". Two women reported this item to be unclear and it was modified to read, "There are other things in my life more important than getting a mammogram." To further tap this concept, item 18 was added, "Getting a mammogram every year is a high priority for me." Under breast self-examination, item 7 was changed to "My breasts are too large for me to perform breast

self-examination correctly". The word "complete" was changed to "perform" and the word "correctly" was added for clarity. Several items use the word "would", such as "...would be too embarrassing" or "...would be too painful". One woman suggested changing this word to "can". This change was made. Finally, two women said that the response choice "No Opinion" did not seem to fit with the items and suggested it be replaced with "Not Sure". This change was made as well.

Two ongoing tasks have continued this year. First, the dataset created during the first year of the grant has been modified to reflect changes to all quantitative instruments. Second, the literature has been updated to stay abreast of current research, particularly in light of the current controversy surrounding the efficacy of the mammography.

Key Research Accomplishments

1) Completed and submitted the annual IRB proposal to New York University and received approval conditional on project site approval and two minor revisions that were submitted.

2) Completed a new IRB proposal for UMDNJ and still awaiting permission to submit.

3) Developed qualitative interview protocol.

4) Piloted qualitative interview protocol.

5) Piloted all quantitative instruments and made required revisions.

6) Updated dataset and data dictionary to reflect instrument modification.

7) Acquired and summarized latest literature pertaining to study topic.

Reportable Outcomes

1) Development of qualitative interview protocol.

2) Piloting of qualitative interview protocol.

3) Piloting of quantitative instruments

Conclusions

Forces at the study site continue to prevent submission of the UMDNJ IRB. This continues to be a major stumbling block towards the beginning of data collection and a continuing source of frustration for the principal investigator. Dr. Richard Montgomery has recently stated that the IRB packet will be accepted for submission within the next several weeks. A turnaround of three days is anticipated for approval, as the survey design nature of this study, along with the fact that patient records will not need to be accessed, will result in an exception status. This is promising news, but with the delay in approval extending into the second year of the grant, it is crucial that this problem be addressed immediately.

With these current IRB issues, data collection efforts continue to be delayed and the principal investigator has not been able to meet Statement of Work deadlines. Time this year, then, has been spent on tasks of a formative nature. It is to be clear that despite not being able to begin data collection, the principal investigator has sought to engage in other tasks necessary of the grant. There is work going on from this end. As already reported, qualitative and quantitative measurements have been developed and piloted. The qualitative interview protocol is now in place and all quantitative instruments are ready for data collection to commence. Ongoing efforts to update pertinent literature as well as the study dataset have also continued.

Upon resolution of IRB issues, the principal investigator will be able to spend 3-4 full days per week in active data collection efforts.

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Annual Summary Report

Appendices

Appendix A: Research Interview Protocol

1) Personal information
    a) How old are you?
    b) What is your country of origin? How long have you lived in this country? In New Jersey?
    c) Are you married? Do you have any children?
2) Knowledge about screening
    a) Can you please tell me what you know about how a women screens for breast cancer? (If they cannot provide any information, prompt for mammography, breast self-exam and clinical breast examination and provide respondent with the patient education screening brochures then skip to question 2c)
    b) Can you describe these to me (prompt for mammography, breast self-exam, clinical breast examination; prompt for their definition of these three methods, how they would describe what is done)
    c) How often do you think a woman your age should go for a mammography?
    d) How often do you think a woman should do breast self-examination?
    e) How often do you think a woman your age should go for a clinical breast examination?
    f) Please describe for me how much you trust the medical community to help you avoid breast cancer. Do you think medical professionals can help you avoid breast cancer? Why or why not?

3) Their own experiences with screening

a. Can you describe for me your experiences with mammography? Can you describe for me your experiences with breast self-examination? Can you describe for me your experiences with clinical breast examination?

b. Tell me about a typical visit to get a mammography (Skip this question if respondent indicates that they have never gone for a mammography and pick up at breast self exam query; if they have a history of mammography, prompt for information regarding access to mammography, any problems getting or keeping appointments for a mammography, where they usually go for a mammography)

c. Thinking about your past experiences getting a mammography, what was the experience like?

d. Describe any concerns you have with getting a mammography.

e. Why did you have the mammography done?

f. How did you know it was time to go for a mammography?

g. Some women do not go for mammography screening. Can you think of any reasons that may keep a woman from getting this test?

h. What kind of things would keep you from going for a mammography?

i. Please describe for me anything that makes you uncomfortable about having a mammography.

j. Do you feel you know how to correctly do a breast self-exam?

k. Talk to me about how comfortable you are doing this exam.

l. How often do you do this exam? (If they do not do it very often, ask them to explain why)

m. Has anyone ever showed you the correct way to do this exam? Would you be interested in that information? Why?

4. Attitudes about screening

a) Do you think screening is an important way of detecting breast cancer? Why or why not?

b) Do you think screening can save lives? Why or why not?

c) Do you think most women go regularly for screening? Why or why not?

d) Please describe for me any advantages you see to going regularly for screening.

e) Please describe for me any disadvantages you see to going regularly for screening.

f) Do you think that certain types of screening are more important to do than others? Explain.

g) What would make you more likely to screen for breast cancer?

h) What would make you less likely to screen for breast cancer?

5. Screening Education

a) Would you be interested in receiving information from me on screening from the American Cancer Society?

b) What type of information would you be interested in?

c) Would you like to receive a referral from me for a mammogram?

d) Has speaking to me today about breast cancer screening made you aware of any fears or concerns you might have?

Appendix B: Qualitative Interview Piloting

Three women over the age of 50 volunteered to be interviewed by the principal investigator for the purpose of piloting the interview protocol. All women were Caribbean-American and worked in the PI's community as in-home childcare providers. All interviews took place in the residences where they are employed. They all reside in a Caribbean-American neighborhood in a New York City borough. They each voiced that they did not want the interview recorded, so notes were taken as the interviews unfolded. Each respondent was instructed to let the interviewer know when a question was either unclear or did not address their experiences with breast cancer screening. Each respondent was screened to exclude anyone who had a personal or family history with breast cancer. What follows is a summary of my comments.

Interview #1: This 54-year-old female from St. Lucia was quite outgoing and well spoken. The respondent indicated that most of the questions were clear and seemed appropriate to the purpose of the interview. She had substantial knowledge regarding mammography and breast self-exam, but had never gone for a clinical breast exam and reported not knowing that this was a common practice. She reported that she was a little uncomfortable talking about breast self-exam and joked that she was equally uncomfortable performing the exam. She reported that she did it, but not very often and felt she was probably not doing it correctly. She reported that question 3a ("Can you describe for me your experiences with breast cancer screening") seemed a little vague and she was not sure exactly what I was asking until I provided her with certain prompts. I asked if any of the questions made her uncomfortable. She reported that she felt a little uncomfortable admitting that she wasn't screening according to medical guidelines and actually thought for a moment about lying to me. This addresses the social desirability assumption that respondents may

feel inclined to tell the interviewer what they believe the interviewer wants to hear and has implications for the validity of the interview data. It might be helpful if the interviewer prefaces the start of the interview with a brief statement about the need for truthful responses and the respondent's right to not answer any questions they feel uncomfortable about. The interview lasted a total of 42 minutes and all questions in the protocol were addressed.

Interview #2: The second respondent was a 58-year-old female from Jamaica. She was well spoken but initially a little shy. I prefaced this interview with the statements referred to in the above paragraph. In many cases, questions were answered in yes/no format, and further prompts were needed to solicit richer information. The respondent reported not liking question 2a ("Do you know the three ways that women can screen for breast cancer?") as she felt "like you are giving me a test or something". Based on this response, that question has since been revised to ask "Can you please tell me what you know about how a women screens for breast cancer?" Question 3a ("Can you describe for me your experiences with breast cancer screening?") elicited an answer that addressed mammography solely. It appears that the interviewer should be ready to prompt for information related to breast self-exam and clinical breast examination if necessary. To question 4b ("Do you think that screening can save lives?") she reported being unsure as "some things are just out of our control". She alluded to more of a reliance on her faith than on the medical community. It is believed by the researcher that this may be a recurring theme during data collection. Based on her answer it was decided to add Question f to the third section of the protocol ("Please describe for me how much you trust the medical community to help you avoid breast cancer? Do you think medical professionals can help you avoid breast cancer? Why or why not?). This interview lasted 34 minutes and it was felt by the researcher that not as much information was elicited from the respondent as had been elicited during the first interview.

Interview #3: The final interview took place with a 50-year-old female from Jamaica. She appeared a little distracted at the start of the interview, and was asked if she might want to reschedule with the investigator. She reported being a little tired but wanted to go on with the interview nonetheless. Like the first respondent, she reported that question 3a was "not clear....I don't know what you want me to say". It appeared that prompting for the three forms of breast cancer screening would be necessary during actual data collection. Once I restated the initial question into three separate questions (i.e., "Can you describe for me your experiences with mammography?"), she was able to provide rich information for each screening modality. Based on this approach, it was decided that this question would be asked as three separate questions during actual data collection. Like the first respondent, she reported feeling a little uncomfortable talking about her experiences with breast self-exam. I asked if she was uncomfortable enough that she did not want to talk about it. She laughed and said "no, it doesn't make me *that* uncomfortable". The researcher is aware now that soliciting this information may be tricky. Respondents must be made aware at the onset that they can refuse to address any questions that make them too uncomfortable. At the same time, while both women reported being a little uncomfortable with this line of inquiry, they proceeded to answer the question nonetheless and provided a rich narrative response. This interview lasted almost 50 minutes.

Summary of three interviews: It appears that for the most part, all questions (with the exception of 3a) are stated clearly. Question 3a has since been modified as noted above. For the most part, the researcher was able to conduct each interview within the 40-45 minute timeframe hoped for. Each respondent reported the interview did not appear to take that long and that they were not tired or bored with it by the end. Each respondent reported wanting to receive any patient-education material I had brought along with me and left the interview with several

brochures. When asked at the end of the interview if talking about breast cancer screening had made them aware of any fears or concerns they might have, each said that speaking with me had made them aware that they are probably not practicing all screening modalities according to medical guidelines. Respondent #1 stated, "It makes you think, should I be doing more?" The researcher needs to be aware that by participating in this interview protocol, respondents risk coming away with conscious fears and concerns about breast cancer and breast cancer screening. As such, it is vital that the researcher be ready to provide the respondents with educational material (i.e., brochures) and access to screening referrals. Dr. Montgomery has already stated that he would be able and willing to facilitate referrals and the investigator has compiled the appropriate education material.

Appendix C: All Quantitative Instrumentation

Code ID: _____ **Date:** _____

Clinician ID: _____

Individual Information Sheet: Demographics and Access to Care Survey

Respondent Source

Current dental clinic patient (receiving dental care) _____
Dental screening patient (treatment not yet begun) _____
Emergency dental patient _____

1. Date of Birth _____ Age _____

2. Place of Birth _____

3. Where do you currently live? _____

4. How long have you lived there? _____

5. How long have you lived in the United States? _____

6. Would you identify your ethnicity as:
   African-American _____
   Caribbean (state which Island) _____
   If not, other (specify) _____

7. Is English your Second Language (ESL) Yes _____ No _____

8. What other languages do you speak? _____

9. When you speak, what is your primary language? _____

10. When you write, what is your primary language? _____

11. When you read, what is your primary language? _____

12. What is your main source of news? _____

13. What are your main sources of information about your community? _____

14. What are your main sources of information about the services in your community?

_____

15. How do you know where to go for medical services?

_____

16. What is your marital status?

Single (never married) _____ Divorced _____
Married _____ Widowed _____
Separated _____

17. How many children do you have? _____

18. Number of births: _____

19. What is your Religious affiliation? _____ _____

I will read you a statement. Please pick the choice you most agree with:

20. I consider myself to have a very strong religious faith:

Strongly agree _____
Agree _____
No opinion _____
Disagree _____
Strongly disagree _____

21. I am a very spiritual person:

Strongly agree _____
Agree _____
No opinion _____
Disagree _____
Strongly disagree _____

22. What is your present occupation? _____

23. How long have you done this work? _____

24. Indicate your highest level of education:

Grades 1-8 _____ Some College _____
Some High School _____ College Graduate _____
High School graduate _____ Graduate school _____
Technical or vocational school _____

25. What is the number of people living in your immediate household? _____

26. Now I am going to ask you who they are:

Spouse/partner _____
Children (how many) _____
Dependent children _____
Non-dependent children _____
Parents (how many) _____
Other (specify) _____

27. What is the total amount of your individual monthly wages, not including benefits (check off choice that applies):

$0.00 - $500.00 _____
$501.00 - $1,000.00 _____
$1,001.00 - $1,500.00 _____
$1,501.00 - $2,000.00 _____
$2,001.00 - $2,500.00 _____
$2,501.00 - $3,000.00 _____
More than $3,000.00 _____

28. What is the total amount of your household monthly wages, not including benefits? (check off choice that applies)

$0.00 - $500.00 _____
$501.00 - $1,000.00 _____
$1,001.00 - $1,500.00 _____
$1,501.00 - $2,000.00 _____
$2,001.00 - $2,500.00 _____
$2,501.00 - $3,000.00 _____
$3,001.00 - $3,500.00 _____
$3,501.00 - $4,000.00 _____
More than $4,000.00 _____
Don't know _____

29. Do you receive any of the following benefits?

Retirement or pension benefits _____
Social Security Pension (SS) _____
Public assistance _____
SSI _____
Social Security Disability (SSD) _____
Veteran's Benefits _____
Unemployment Insurance _____
AFDC _____
Medicaid _____
Medicare _____
Any other benefits (specify) _____

30. Do you have health insurance at this time? Yes ____ No _____

(a) If yes, what kind _____
(b) If yes, who is the insured? _____
(c) If yes, how long in this plan _____

31. Think back over the last year about the different medical services you received. In the last year have you:

Seen a doctor	Yes _____	No _____
Had a physical examination	Yes _____	No _____
Seen a gynecologist	Yes _____	No _____
Seen a dentist	Yes _____	No _____
Seen a nurse practitioner	Yes _____	No _____
Seen a healer	Yes _____	No _____
Seen a chiropractor	Yes _____	No _____
Seen an acupuncturist	Yes _____	No _____
Seen a homeopathic	Yes _____	No _____
Seen an herbalist	Yes _____	No _____
Seen a hypnotist	Yes _____	No _____

32. Overall, how satisfied are you with the medical services you receive:

Very satisfied _____
Satisfied _____
Somewhat satisfied _____
No Opinion _____
Somewhat dissatisfied _____
Dissatisfied _____
Very dissatisfied _____

33. What is the biggest problem in getting a doctor's appointment?

(Check all that apply)
None _____
Finding a doctor _____
Contacting the medical office _____
Getting through to someone who can help with appt. _____
Getting an appointment that fits my schedule _____
Other (detail) _____

34. What is the biggest problem in keeping a doctor's appointment?

(Check all that apply):
None _____
Sudden change in schedule _____
Getting to the medical office _____
Finding childcare _____
Other _____

35. What is the biggest problem when attending the doctor's appointment?

(Check all that apply)
None _____
Waiting to be seen by the medical professional _____
Being sent to other doctors for additional evaluation _____

Being sent for additional lab work _____
Filling out all the paperwork _____
Problems with health insurance _____
Paying for the medical services _____
Other (describe) _____

36. Do you have any problems with your health coverage? Yes ___ No ____
(Please describe)

_____
_____
_____

37. Do you have a chronic illness? Yes _____ No _____

38. What type of chronic illness do you have? (List all) _____

39. Do you take medication at the present time? Yes _____ No _____

40. What kind of medications do you take for your chronic illness? (List all)

_____
_____

41. How satisfied are you with the medical care you get for chronic disease?

Very satisfied _____
Satisfied _____
Somewhat satisfied _____
No opinion _____
Somewhat dissatisfied _____
Dissatisfied _____
Very dissatisfied _____

(If respondent provides narrative, list it here):

_____
_____

42. What are some factors that might keep you from using medical services when you need them? List any that apply.

_____
_____
_____

43. What are some factors that encourage you to use medical services when you need them? List any that apply.

_____
_____
_____

44. What do you like most about the medical care you receive?

_____

_____

45. What do you like least about the medical care you receive?

_____

_____

46. How did you get to your appointment today?

Drove myself _____ Got a ride _____
Cab _____ Walked _____
Bus _____ Ambulette _____
Train _____ Other _____

47. How do you usually get to your medical appointments?

Drove myself _____ Got a ride _____
Cab _____ Walked _____
Bus _____ Ambulette _____
Train _____ Other _____

48. How much average time does a medical appointment take from the moment you leave for the appointment till the moment you return? _____

49. Besides the cost of the medical visit, on average, what is the financial cost for you to get to an appointment? (Include carfare, bus or train fare, childcare, lost time from work)

_____

50. Do you usually travel to medical appointments?

From your home _____
From your job _____
Other (specify) _____

51. Do you go to different locations for different medical services? Yes _____ No _____

52. How often do you go to different locations for different medical services?

Always _____
Often _____
Sometimes _____
Rarely _____
Never _____

53. How often to you have to go to different locations for different services?

Never _____ Rarely _____ Sometimes _____
Often _____ Always _____

54. Do you know if there is a health clinic within close distance to you? Yes _____ No _____

55. If yes, how often do you use the services there?

Most of the time _____
Some of the time _____
Rarely _____
Never _____

56. How would you rate your travel to and from medical appointments?

Very easy _____
Easy _____
Difficult _____
Very difficult _____

57. Do you have any limitations or handicaps that keep you from getting medical care when you need it? Yes _____ No _____ If yes, explain:

_____
_____

Please tell me how much you agree with the following statements:

58. I trust my health care providers to give me the proper medical care:

Strongly agree _____
Agree _____
No opinion _____
Disagree _____
Strongly disagree _____

59. I trust my health care providers when they make suggestions on how I can best take care of myself:

Strongly agree _____
Agree _____
No opinion _____
Disagree _____
Strongly disagree _____

60. I trust my health care providers when they prescribe medication for me:

Strongly agree _____
Agree _____
No opinion _____
Disagree _____
Strongly disagree _____

(Please fill in the blank for the next three items)

61. I would feel better about my medical care if:

_____
_____

62. I would feel better about my medical care if my health care provider would:

_____

_____

63. I would feel better about my medical care if my health insurance carrier would:

_____

_____

64. When my health care provider prescribes medication for me, I

(a) Closely follow their instructions:
Always_____Usually _____ Sometimes _____ Never _____

(b) Fill my prescription:
Always_____ Usually _____ Sometimes _____ Never _____

(c) Take the entire prescription
Always_____ Usually _____ Sometimes _____ Never _____

(d) Trust that the medication will make me feel better:
Always_____ Usually _____ Sometimes _____ Never _____

(e) Worry that the medication will have side effects:
Always_____ Usually _____ Sometimes _____ Never _____

(If respondent provides narrative, list it here):

_____

_____

65. When my health care provider makes recommendations about how I can improve my health, I:

(a) Closely follow their instructions:
Always_____ Usually _____ Sometimes _____ Never _____

(b) Agree with their recommendations:
Always_____ Usually _____ Sometimes _____ Never _____

(c) Understand their recommendations:
Always_____ Usually _____ Sometimes _____ Never _____

(d) Trust their recommendations:
Always_____ Usually _____ Sometimes _____ Never _____

(If respondent provides narrative, list if here):

_____

_____

66. When I do follow my health care providers' recommendations, it is usually because:

_____

_____

_____

67. When I do not follow my health care providers' recommendations, it is usually because:_____

_____

_____

68. In the last 12 months, how many times did you go to the emergency room for medical care:

None _____ Fill in number of times _____

69. In the last twelve months, not counting visits to the emergency room, how many times have you gone to a doctor's office or clinic:

List number of times _____

70. In the last twelve months, my health insurance plan caused delays in my health care:

Strongly agree _____
Agree _____
Not sure _____
Disagree _____
Strongly Disagree _____

71. When I go to see a doctor they usually explain things to me in a way that I can understand:

Strongly agree _____
Agree _____
Not sure _____
Disagree _____
Strongly Disagree _____

72. When I go to see a doctor they usually treat me with respect:

Strongly agree _____
Agree _____
Not sure _____
Disagree _____
Strongly Disagree _____

73. When I go to see a doctor, the office staff usually treats me with respect:

Strongly agree _____
Agree _____
Not sure _____
Disagree _____
Strongly Disagree _____

74. When I go see a doctor they usually listen carefully to what I have to say:

Strongly agree _____
Agree _____
Not sure _____
Disagree _____
Strongly Agree _____

CODE ID: _____ Date _____

Intent to Breast Cancer Screen

We are very interested in learning about your thoughts on breast cancer screening. Please respond to each statement honestly. There are no right or wrong answers. List your level of agreement with each statement using the following scale:

1 Strongly Disagree	2 Disagree	3 Not Sure	4 Agree	5 Strongly Agree

1) I plan on having a mammogram sometime next year. _____

2) I plan on performing breast self-examination sometime next year. _____

3) I plan on performing breast self-examination several times next year. _____

4) I haven't really thought about having a mammogram this coming year. _____

5) I plan on performing breast self-examination once a month. _____

6) I have no intention of scheduling a mammogram this coming year. _____

7) I haven't really thought about performing breast self-examination in the future. _____

8) I plan on having a breast examination done by a health care professional sometime next year. _____

9) I have no intention of performing breast self-examination in the coming year. _____

10) I haven't really thought about scheduling a breast examination in the future. _____

11) I have no intention of scheduling a breast examination in the coming year. _____

Quick Patient History: Criteria for Inclusion/Exclusion from Study

1) Age
2) Health insurance
   Yes _____ No _____
   Type _____

3) Health status
   Excellent_____ Good_____ Fair _____ Poor _____

4) Chronic health problems (list):

_____
_____
_____

5) Chronic disease (list):

_____
_____
_____

6) Personal history of breast cancer:
   Abnormal mammography _____
   Breast cancer diagnosis _____
   If so, when _____

7) Family history of breast cancer:
   Which family member(s): _____
   Abnormal mammography _____
   Breast cancer diagnosis _____
   If so, when _____
   Survivor or Mortality (date) _____

8) Ethnic background:
   Country of origin _____
   Identify as: African American _____
   Caribbean Amerian _____
   If so, which region _____
   Other _____

9) Screening history:
   Breast self-exam: Y____ N _____ Frequency _____ Last done _____
   Clinical self-exam: Y____ N _____Frequency _____ Last done _____
   Mammography: Y____ N _____ Frequency _____ Last done _____

Code ID: _____ Date: _____

Screening Beliefs Scale
(Champion & Scott, 1997)

Please list your level of agreement with each statement using the following scale:

1	2	3	4	5
Strongly Disagree	**Disagree**	**Not Sure**	**Agree**	**Strongly Agree**

Mammogram:

1) Having a mammography will help me find breast lumps early. _____

2) I am afraid to find out there is something wrong when I have a mammogram. _____

3) I cannot remember to schedule an appointment for a mammogram. _____

4) Having a mammogram will decrease my chances of dying from breast cancer. _____

5) Having a mammogram costs too much money. _____

6) People doing the mammogram are rude to women. _____

7) If I find a lump early through mammogram my treatment for breast cancer may not be as bad. _____

8) Having a mammogram would expose me to unnecessary radiation. _____

9) Having a mammogram can be too embarrassing. _____

10) Having a mammogram is the best way for me to find a very small breast lump. _____

11) There are other things in my life more important than getting a mammogram. _____

12) Having a mammogram would take too much time. _____

13) It is difficult to get transportation for a mammogram. _____

14) Having a mammogram can be painful. _____

15) I don't know how to go about scheduling a mammogram. _____

16) It is difficult to get childcare so I can get a mammogram. _____

17) I am afraid to have a mammogram because I don't understand what will be done. _____

18) Getting a mammogram every year (every other year) is a high priority for me. _____

Breast self-examination:

1) When I do breast self exam I am doing something to take care of myself. _____

2) Breast self exam is embarrassing to me. _____

3) I do not feel I can do breast examination correctly. _____

1	2	3	4	5
Strongly Disagree	**Disagree**	**Not Sure**	**Agree**	**Strongly Agree**

4) If I find a lump early through breast exam, my treatment for breast cancer may not be as bad. _____

5) Breast self-exam is not necessary if I have a routine mammogram. _____

6) Breast self-exam takes too much time. _____

7) My breasts are too large for me to complete breast self-examination. _____

8) Completing breast self-exam each month may help me to find breast lumps early. _____

9) It is hard to remember to do breast self-exam. _____

10) Breast self-exam is not necessary if you have a breast exam done by a health care provider. _____

11) My breasts are too lumpy for me to perform breast examination correctly. _____

12) Completing breast self exam each month may decrease my chances of dying from breast cancer. _____

13) Doing breast self-exam will make me worry that something is wrong with my breast. _____

14) I don't have enough privacy to do breast self-examination. _____

15) I have other problems more important than doing breast self-examination. _____

16) I know how to perform breast self-examination. _____

17) I would be able to find a breast lump the size of a pea. _____

18) I can perform breast self-examination correctly. _____

19) I could find a breast lump by performing breast self-examination. _____

20) I am able to find a breast lump which is the size of a quarter. _____

21) I am able to find a breast lump which is the size of a dime. _____

22) I am sure of the steps to follow for doing breast self-examination. _____

23) I would be able to tell something is wrong with my breasts when doing breast self-examination _____

24) I am able to tell something is wrong with my breasts by looking in the mirror. _____

25) I can use the correct part of my fingers when examining by breasts. _____

Code ID: _____ Date: _____

Breast Cancer Screening Practices

(Saint-Germain & Longman, 1993)

We are very interested in learning about your experiences with breast cancer screening. Please answer each question honestly. There are no right or wrong answers to these questions.

1) Have you ever had a mammogram ? Yes_____ No _____

2) Have you had at least two mammograms? Yes _____ No _____

3) Have you had at least three mammograms? Yes _____ No _____

4) Have you had two mammograms in the past two years? Yes _____ No _____

5) Have you had three mammograms in the past three years? Yes _____ No _____

6) Have you ever had a breast examination by a health care provider? Yes _____ No _____

7) Have you had a breast examination in the last year? Yes _____ No _____

8) Have you ever done a breast self-examination? Yes _____ No _____

9) Did you perform a breast self-exam in the last year? Yes _____ No _____

10) On average, how many times per year do you perform breast self-examination. _____